



# Quality Account 2022/23



We care for children, young people and families in the East Midlands – wherever they are.  
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## Our Vision, Mission and Values

### Our Vision

**The Rainbows experience wherever you are.**

### Our Mission

**Across the East Midlands we will:**

- Transform care for those Children and Young People who have a life-limiting/life-threatening condition
- Relieve the pain and symptoms associated with life-limiting/life threatening conditions
- Support every child and young person to achieve their full potential
- Create memories for families to treasure
- Provide comfort and compassion at the time of and following the death of a child or young person



## Our Values

...because **WE CARE** we are:

Our Values	Evidenced by
Welcoming	<ul style="list-style-type: none"> <li>• we will welcome you to Rainbows with a smile and open arms. If you are a family member please make yourself at home, if you are a supporter thank you, we are so grateful to you. If you are a colleague, volunteer or trustee we will value your contribution</li> <li>• we will have a positive “can do” attitude, which we will demonstrate every day, through our body language and behaviour</li> <li>• we will treat everyone as we would like to be treated and will consider other’s needs as well as our own, embracing and valuing differences. We will see everyone as an equally important link in the chain</li> <li>• we will support others personally and professionally, especially when they are struggling or managing a stressful situation</li> <li>• we will demonstrate care and compassion to everyone all of the time</li> </ul>
Excellent	<ul style="list-style-type: none"> <li>• we will work hard to be the best we can be at everything we do and we will play our part in helping others to achieve the same. We will constantly look for ways to be outstanding in all of our work</li> <li>• we will listen, we will learn and we will lead. We will be the best we can be in order to offer exceptional service</li> <li>• we will deliver care that reflects best practice and clinical excellence, and we will be outstanding across the whole of the organisation</li> <li>• we will actively participate in our development plans, using the appraisal process and taking personal responsibility. We will keep up to date with statutory training and access appropriate training opportunities</li> <li>• we will encourage people to be open about mistakes and how we can learn from them</li> </ul>
Co-operative	<ul style="list-style-type: none"> <li>• we will work together to create the best possible outcome for families, which is our single unifying goal</li> <li>• we will take on board others’ views and welcome feedback on how we could do things better</li> <li>• we will develop trust through openness, honesty and consistency, to ensure that everyone feels safe to speak up and that people feel able to voice their views in an appropriate manner</li> <li>• we will frame meetings and discussions with a positive message at the start and remain solution focused throughout</li> <li>• we will demonstrate Rainbows values in all that we do and we consider the impact that our behaviour has on others, either positive or negative</li> </ul>

Our Values	Evidenced by
Accepting	<ul style="list-style-type: none"> <li>• we will accept everyone because everyone matters. We will respect and embrace the differences amongst the diverse communities we serve</li> <li>• we will be accepting and supportive of change, which includes seeking accurate information about the changes. We will constructively challenge proposals for change if we do not agree and offer alternative suggestions</li> <li>• we will politely challenge inappropriate behaviour or poor working practices</li> <li>• we will always seek accurate information and not contribute to Rainbows rumours</li> <li>• we will accept other people's strengths and weaknesses and should not assume we are all the same</li> </ul>
Responsive	<ul style="list-style-type: none"> <li>• we will listen and we will learn. We will rise to the challenges we face and we will not give up. We will try new things and develop new services to meet increasing and changing needs</li> <li>• we will do what we say we will do and hold others, respectfully to account for their actions and behaviours and ourselves. Alternatively, we will provide an explanation if we are delayed or no longer able</li> <li>• we will work proactively and collaboratively, responding to different team's needs</li> <li>• we will constructively feedback to others and be willing to receive feedback</li> <li>• we will try to see a situation from the viewpoint of others and respond in an appropriate way, considering what it must feel like to be in someone else's shoes</li> </ul>
Energetic	<ul style="list-style-type: none"> <li>• we will go above and beyond and we will make sure the efforts we put in matches our ambition. We hope our energy is infectious</li> <li>• we will work together and celebrate together. We will cooperate as a team and acknowledge each other's success and achievements</li> <li>• we will actively communicate the right information at the right time. We will be open and transparent at all times, helping and guiding each other</li> <li>• we will show commitment to demonstrating the Rainbows values and we will aim to be the best we can be</li> <li>• we will set ourselves stretching goals going the extra mile where possible, to make a difference to others and to maintain the reputation of Rainbows</li> </ul>



### Part One

#### Statement of Quality by the CEO

This is our tenth Annual Quality Account and covers the period between 1 April 2021 to 31 March 2022. I write this statement in the context of a continuing pandemic, and whilst we hope that we will return to 'normality' soon, the economic and social disruption caused by the pandemic is devastating and the long-term effect on our wellbeing is not yet fully understood. What we do know, is the impact on our children, young people and their families is profound and now more than ever, they need access to the expertise and support that Rainbows offers.

As well as continuing to provide vital end of life care and symptom control for those children who simply do not live long enough, we have made real progress towards our challenging ambition to reach more children and young people. This is part of a whole system approach and we are very proud of the work we have done with our partners and the development of a Rainbows service in our hospitals.

Our people are our greatest asset and we recognise the current demands on our staff and volunteers. We remain committed to providing our people with the tools, resources and skills they need to be the best they can be.

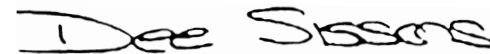
Over the last year, we have invested in a large-scale IT programme that will help transform the way our staff and volunteers work. Their well-being is of paramount importance to us and we will continue to build on our well-being program. Most importantly, we continue to improve our communications, particularly in relation to how we tell our story to staff and how we hear about their concerns or challenges.

I am proud of all our staff, the quality of care that the clinical team provide and the creativity and incredible resilience of staff across the whole of the organisation. Especially in dealing with the challenges we face in these unprecedented circumstances.

We know there are challenges ahead and the full impact of Covid-19 is not yet known. However, we couldn't deliver our essential services without our supporters, and we would like to take this opportunity to thank them for keeping Rainbows in their heart and in their mind.

The pandemic has reminded us of our mortality and we want to offer our heartfelt condolences to anyone who has experienced loss and bereavement during these difficult times.

To the best of my knowledge, the information reported in this Quality Account is an accurate and fair representation of the quality of services provided by Rainbows Hospice for Children and Young People. We hope you find this Quality Account both informative and useful and please do not hesitate to contact us with any questions or comments that you may have.



Dee Sissons

Chief Executive Officer



### Part Two

#### What we achieved in 2021/22

##### In line with our Strategy, Rainbows identified the following priorities for 2021/22

When our quality account was written last year, no-one expected that we would be experiencing an ongoing Global Pandemic. This, as in all health and social care services, has impacted our work programme and priorities set out last year. Our focus and priority has been to ensure the safety of our children, young people, families and staff during these unprecedented times. Despite this we have made progress on all of our priorities.

#### Future Planning – Patient Safety

##### Priority 1: To ensure we deliver all services in a Covid secure way

Policies and procedures are in place as we move to the new normal of living with Covid-19. Procedures enable us to step up or step down precautions in line with the Health Security Agency ensuring children, young people, families and staff remain safe when using or working within our services. This has included using technology to continue to provide high quality services such as virtual family support and contact, virtual support groups as well as Zoom family fun day activities, World Book Day and Christmas parties. Pre-admission care planning led by our admissions nurses has further supported not only a safe admission, but reduced the length of time this takes. Numbers of children and families staying has been reduced to enable social distancing and testing for all those working, staying or visiting Rainbows has been in place since July 2021.

A number of our nurses were involved in delivering the national vaccination programme in 2021. Our links with the local hospitals were further strengthened as we were able to reduce the pressure on beds and support the safe but early discharge of medically fit children home, by admitting to Rainbows to complete treatment or await community care packages. We have also been able to support clinical skills training for families prior to going home.

##### Priority 2: Focus on clinical skills and education for new and adapted services to ensure we have a workforce fit for the future

The Lead for Education has been in post since March 2021 and following a full review of clinical training and education at Rainbows, a strategy to modernise and embed statutory, mandatory and essential clinical skills and competencies has been developed. Two part time Clinical Skills Facilitators have been recruited to lead this with the Care and Family Support Teams. The Lead for Education is leading a number of training pathways in line with our strategy; Long Term Ventilation, Education, End of Life/palliative care and Leadership. Rainbows established a “learning hub” in 2021, a resource room for training which includes training mannequins and a bed space set up for training in Long Term Ventilation (LTV) and clinical skills such as catheterisation and enteral feeding.

Review and relaunch of preceptorship programme for newly qualified nurses took place in 2021.

Networking and partnership with other hospices, NHS trusts and training providers continues with a partnership arrangement in place with Leicester Partnership Trusts Speech and Language Department.

### Future Planning – Clinical Effectiveness

#### Priority 1: Implement a new Care IT system and database

Work to implement the new clinical database continues with SystmOne Palliative Care being our new system. Go live date was achieved in February 2022. Training and embedding the system is ongoing. The system allows us to have increased joined up care for Children and Young People (CYP), increased ability and quality of reporting, reduced risk of paper documentation. Along-side this we are also working towards electronic archiving of historic notes.

#### Priority 2: Implementation of the Rainbows in Hospital Service

We successfully appointed four Rainbows Nurses in our tertiary hospitals – in Paediatrics and Neonatal services, the first started in May 2021 and we are seeing improved reach and quality palliative care for these children.

The first Specialist Paediatric Palliative Care Consultant was appointed in May 2021 at University Hospitals of Leicester, the post works in conjunction with the hospital nurses and provides specialist palliative care to children in hospital.

We have also seen increased referrals to Rainbows services for children who may not have been referred otherwise.

### Future Planning – Patient Experience

#### Priority 1: Involve children and young people and families in the development of future community outreach model

We appointed an external review team in August 2021 to look at our existing community services including family support and the needs of our CYP in the community. Families and CYP will be engaged in this review and their views taken into account. The review is expected to be completed in April 2022 and will inform the future direction of Rainbows community and outreach services.

#### Priority 2: Improve & remodel the physical environment

A number of bathroom facilities in the Hospice have undergone refurbishment and updating with the support of a grant from Severn Trent Water. This has improved the experience of our CYP whilst staying in the Hospice, incorporating therapeutic elements of the bathrooms.

We are engaging an architect in 2022 to look at how we can effectively use the available space to improve the facilities in the building as part of the Space Project.

We have also started work on our ambition to be 'net zero' by 2030, including installation of electric car charging points at the Hospice.





### Millie's Story

In May 2021 Rainbows implemented Palliative Care Clinical Nurse Specialists in Hospital. Very quickly the positive impact of these roles was demonstrated. The case study below shares 'Millie's story'. The Rainbows Nurse in hospital impacted on Millie's journey in many ways including timely access to symptom management and the hospice services.

Millie was 17 when she was referred to Rainbows from the hospital. She had been diagnosed with a rare complex cancer and despite treatment she had relapsed and there was no hope of a cure.

The ward contacted the new Rainbows Nurse at the hospital (Katie, pictured) as Millie was presenting with symptoms that were difficult to manage. Millie was in significant pain and it was felt that the pain was not just physical but holistic. Katie spent time with Millie and her family; she spoke to them about Rainbows and how we may be able to help.

Millie was admitted to Rainbows from hospital for symptom management. When she arrived, she was unable to mobilise and was so doubled up with pain she needed help with everything including personal care.

During her initial stay at Rainbows Millie's physical pain was controlled by the Clinical Nurse Specialist working alongside the Medical Team to get the right balance of medication that enabled relief without excessive sleepiness. In addition to this she was given an opportunity to explore her

feelings, treatment and decisions with the specialist staff at Rainbows. Her teenage sister was also given an opportunity to explore her feelings and received support from the Sibling Support Worker.

With her physical, emotional and spiritual pain being acknowledged and managed Millie enjoyed her stay at Rainbows. She spent time with her family and was able to enjoy her hobbies of painting and cooking.

When Millie went home she was able to walk to the car and also walk up the stairs to her bedroom at home. She could also manage her personal care that was so important to her. Shortly afterwards she was admitted to hospital for a routine procedure; the staff in the hospital commented on the improvement in Millie's symptoms. Katie spent time with the family again and Millie expressed she felt 'transformed.'

At home Millie and her family received regular support from the local Community Nursing Team and Rainbows staff worked in partnership with them to ensure her symptoms remained controlled. Millie wanted to stay at home for as long as she could and she managed this for some months. When her condition deteriorated she was admitted to Rainbows, where she peacefully died with her family around her.



## Part Three

### Priorities for improvement 2021/22

#### Future Planning – Patient Safety

##### **Priority 1: Implement a digital risk register using the Datix system & develop a pan organisational process**

Moving our paper-based process to a digital system will bring us in line with our digital aspirations and support monitoring, review and update of the risk register in a timely way, ensuring a consistent and joined-up approach to risk management across the organisation. The system will enable risks to be assigned to owners who will be prompted to review and manage any actions, which will in turn ensure effective risk management.

##### **Priority 2: Develop & implement Hospice metrics to demonstrate compliance with standards & evidence continuous improvement**

Collection of Hospice metrics will bring together monitoring and compliance of quantitative and qualitative data into one central document including patient safety initiatives / standards, clinical incidents (including medicines) and actions and learning from these, audit results and actions (including record keeping, medicine charts, tissue viability), infection prevention standards, occupancy statistics, dependency assessments and day to day procedures and monitoring tools. The gathering of this data centrally can then be used to inform nursing and clinical decisions, drive improvement and identify areas which require further focussed work.



### Future Planning – Clinical Effectiveness

#### Priority 1: Embed the new Care IT system and HR database

With the initial training for the Rainbows SystmOne Palliative module complete and go live achieved in February 2022 we are moving forward with further training and embedding the system enabling staff to use it to its full potential, allowing us better communication and information sharing with other professionals involved in the CYP's care. Over the next year with the support of a SystmOne administrator our Family Support and Care Teams will become used to using tablets, laptops and computers for all record keeping, eventually making our documentation and record keeping as paperless as possible!

A new HR Database has been decided upon by the Director of People and HR team and they will be working hard to get this up and running, allowing us to collate many bits of information in one place ensuring better management of staff and communication between teams across the organisation and HR.

#### Priority 2: Rainbows Admissions Nurses

Our Rainbows Admissions Nurses have been in post since just before the start of the pandemic, but due to the pandemic had not been able to get the service fully off the ground. Since we were able to restart our planned short breaks in May 2021 they have been working hard to create a pre-admission service that works for both the families and care team staff. Embedding the practice of pre-admissions being carried out for all planned short break bookings will enable the care team staff to spend less time doing the admission procedure on the day CYP's arrive for their stay. The pre-admission allows families the time to ask questions, update care plans and for the admissions nurses to ensure parents and carers are aware of what they need to do to have a smooth and quick admission on the day they arrive. The service will lead to a better admission process all round.

### Future Planning – Patient Experience

#### Priority 1: Implement the “voice of the child” survey at Rainbows

Rainbows wants to hear the voice of children and young people who use our services and will use the results of this survey to ensure the services we offer are of value to children and young people and that their care is shaped around their needs. This survey undertaken twice a year with all CYP over the age of five years using Rainbows, will not only ask what services they used but also if there were activities or services they would have like to have used but didn't and the reasons why. We will also ask for an overall rating of their stay.

#### Priority 2: Introduce NHS England Improvement Fifteen Steps Challenge

The introduction of the 15 steps toolkit will form part of our programme of continuous improvement, helping us to understand quality care from a patient or family perspective. It offers a series of questions and prompts to help us understand the first impressions experienced by children, young people and their families when they arrive at Rainbows and therefore help us to make improvements in the way in which we welcome families and how they experience care, kindness and compassion. This will not only look at care but the environment as well. The pool of 15 steps assessors will be recruited from families, young people and clinical and non-clinical staff and therefore give us a rounded unique perspective.



### Part Four

#### Statements of Assurance

**There is a legal requirement for us to report on the following. These statements identify our position as set in the Quality Account Regulations.**

#### Review of Services (mandatory statement):

Rainbows is a nurse-led hospice providing care and support for children and young people with life-limiting conditions from birth to 25 years of age and their families. A team of GP's supports us Monday - Friday with a 24/7 on-call service. In May 2021 we appointed a Specialist Paediatric Palliative Care Consultant at University Hospitals Leicester (UHL), who provides support & advice to our GP team and across the Network.

During 2021/22 Rainbows provided the following services to the NHS

- hospice services - short breaks, symptom management and End of Life Care
- day care services - suspended March 2020 due to the Covid-19 Pandemic
- psycho-social family support services
- specialist palliative care advice and support
- support to the NHS during Covid Pandemic, including ongoing step down services, Covid-19 vaccinations and workforce sharing

Rainbows have reviewed all the data available to us on the quality of our services. Our Clinical Quality Assurance Committee (CQAC) chaired by a Clinical Trustee, meets quarterly. The Committee is provided with reports for assurance on the quality of care we provide, including clinical incidents and clinical audit compliance. CQAC submits a quarterly report to our Board of Trustees.

All Rainbows services are funded through a combination of fundraising activity and/or contracts with NHS and Social Care Commissioners. Where NHS and Social Care funding is secured, this only partly

contributes to the costs of clinical care of children and young people. Additional costs are supported by the charity and we are dependent on our fundraising activity. This income enables us to offer enhanced services to our families, including; music therapy, art therapy, complementary therapy, family accommodation, hospitality and bereavement support. In addition, on-going supplies and provisions, costs of maintaining the hospice buildings and gardens are also reliant upon fundraising/charitable income.

A focus of our work in 2022/23 will be to further develop our relationships with commissioners and to increase Clinical Commissioning Funding from the NHS, by continuing to support NHS services with long term ventilation needs and step down of children who are medically fit for discharge. We will also continue to develop our Rainbows in Hospital services and aim to have a Rainbows Nurse in all hospitals across the East Midlands by 2023. Rainbows is working closely with the newly formed Integrated Care Boards to ensure recognition of the services we provide'

We will use the external review of our community/outreach services to inform our future services and workforce planning in the community.

Our strategic priorities for 2021/25 aim to extend our services to reach more families of children and young people with a life limiting condition across the East Midlands:

- Rainbows in hospital
- Rainbows at Lark Rise
- Rainbows in the community

**"The Rainbows experience wherever you are"**

### Financial Considerations

The income provided by the NHSE grants and statutory funding in 2021/22 was £878,000

The remainder (86%) of the funds needed to run Rainbows services is generated through donations, legacies, fundraising events, retail shops and lottery.

### Information Governance

Rainbows have updated their information governance policies and procedures in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018; and have continued to manage personal data in line with this legislation.

### Clinical Coding Error Rate

Rainbows was not eligible to submit data to the Summary Hospital-level Mortality Indicator (SHMI) during the period 2021/22. Rainbows are not subject to the Payment by Results clinical coding audit during 2021/22 by the Audit Commission.

### Data Quality

In 2021/22, Rainbows collected and submitted the following:

- internal activity/performance data to Clinical Quality Assurance Committee, Corporate Governance Committee and Board of Trustees
- child/young person specific data to CCGs
- annual data to Together for Short Lives
- child death data to Child Death Overview Panel
- data for the Safeguarding Audit Tool

### Participation in National Audits

In 2021/22 there were no audits or enquiries relating specifically to specialist children's palliative care.

### Local Clinical Audits

The Rainbows Audit and Quality Improvement (QI) Committee continue to meet quarterly to drive improvement across the Hospice with a consistent approach to audit with common understanding across the Hospice. We are supporting a number of audit and QI projects across the Organisation including:

- Mini Mouth Care Matters – An audit and QI project led by Kings College London ensuring good mouth care is embedded in clinical practice.
- Admissions Audit – lead by the admissions nurses looking at the impact of the pre-admission process and ensuring safe and effective admissions and compliance against our standards for medicines and record keeping.
- The introduction of the 15 steps Challenge
- The Voice of the Child Survey

A programme of local clinical audits is still undertaken each year as part of the on-going quality and performance monitoring and review process. These include mixed sex accommodation, hand hygiene, IPC, PPE, medication management, tissue viability and record keeping. And new for 2021 a Covid-19 environmental audit. We use national audit tools specifically developed for hospices. The audit tools have been peer reviewed and quality assessed. This allows us to monitor the quality of care Rainbows provide in a systematic way and creates a framework by which Rainbows can review this information and make improvements.



### Local Clinical Audits (Continued)

CQAC and Corporate Governance committee approves the audit schedule for the coming year, which includes clinical and non-clinical audit. Priorities are selected in accordance with our statutory and regulated requirements and any areas where a formal audit would inform our risk management. For assurance, audit results are reported to and discussed at CQAC and the Board of Trustees. See appendix 1.

Medicines Management and Storage of Controlled Drugs has external oversight when it is audited by University Hospitals of Leicester pharmacy team twice a year. The outcome of most recent audit in November 2021 was exemplary with no further action required. This is the second year running where audit compliance has been 100%

In December 2019, the Executive Nurse and Lead Nurse for Quality and Governance completed a Clinical Governance review resulting in a comprehensive Quality Improvement Plan (QulP). The QulP has formed a framework of continuous improvement for the clinical teams and is monitored through The Good Clinical Governance Committee and progress reported to CQAC quarterly. A process for identifying and adding improvements and actions has been developed to make this a Continuous Improvement Plan.

### Infection Prevention & Control (IPC)

Infection Prevention and Control procedures and risk based approach have formed the bedrock of our response to the national Covid-19 pandemic with standard and enhanced precautions continuing to be part of everyday practice. A suite of robust and vital Standard Operating Procedures including Isolation of suspected and confirmed cases, CYP, family and staff testing and the use of Personal Protective Equipment (PPE) have been written and developed which have underpinned our response to the pandemic and our move towards living with Covid-19, to ensure everyone using and working at Rainbows remains safe. There have been no Hospice Acquired Infections (HAI's) among children, young people and their families in 2020/2021, including Covid-19. An outbreak within the clinical staff team of Covid-19 occurred in December 2021 but was community acquired.

A number of measures in line with the Health Security Agency and their advice were put into place alongside a hospice "lockdown" including increased monitoring of hand hygiene and correct use of PPE, as well as increased lateral flow testing and further reducing footfall whilst maintaining a service. We have continued to be supported remotely by Partner IPC lead at University Hospitals of Leicester- the last physical audit took place in March 2020 - the audit showed 91% compliance. This is due to be repeated in March 2022 as the Hospice opens up again to external and vital inspection and support. However, internal monthly IPC audits have continued with high compliance.

Our Comprehensive Business Continuity Plans for both local and National Outbreak continue to be implemented and reviewed regularly. The Executive Nurse is Rainbows nominated Lead for Covid-19.

### MHRA & Patient Safety Alerts

All alerts received are reviewed by the Senior Nurses to assess relevance to Rainbows. All relevant alerts received are noted at Good Clinical Governance meeting and have had appropriate action taken. 2020/21 saw a number of new national guidelines developed in response to Covid-19 - Rainbows has implemented all of these as required.

### Research

Rainbows has continued to develop its Research activity and has now appointed a Research Manager. We now have robust policies and procedures in place compliant with research regulations, to enable us to participate in and undertake research in relation to Paediatric Palliative Care. In 2021/22 Rainbows have participated in twelve Paediatric Palliative Care Research Projects as Participant Identification Centre (PIC) Site. We have also developed Research collaborations with:

- NIHR East Midlands Clinical Research Network (EMCRN)
- Together for Short Lives
- Martin House Research Centre (York)

### Part Five

#### What Others Say About Us

##### CQC:

COPE Children's Trust (trading as Rainbows Hospice for Children and Young People) is registered by the Care Quality Commission (CQC) under the Health and Social Care Act (2008) and has the following conditions of registration that apply:

- treatment of disease, disorder or injury

Rainbows are subject to periodic reviews by the CQC and the last review an unannounced on-site inspection took place from 31 May to 2 June 2016. Rainbows are fully compliant and rated as low risk. The overall rating was Outstanding.

Rainbows are required to register with the CQC and our current registration status is unconditional. The CQC did not take any enforcement action against us and Rainbows were not required to participate in any special reviews or investigations by the CQC during 2020/21.

A CQC Transitional Monitoring Assessment was carried out in February 2021 - No areas of concern were raised.

No further concerns, inspections or TMA's in 2021/22

##### **Paid Person's Representative (PPR)**

A PPR visited a young person at the hospice and reviewed his clinical record. He found that ALL care plans were relevant and up-to-date, and the relevant mental capacity assessments and best interest documentation was in place. He fed back that he was very impressed by the progress made.

This feedback is very significant – not just from a compliance perspective, but also because it indicates a personalised approach to care where the young person's 'voice' is present and we are treating him as an adult and affording him the same rights as others who can make decisions for themselves.

##### **Commissioner Quality Assurance Visits:**

There have been no Commissioner Quality visits this year due to the Pandemic. Quality reports continue to be submitted quarterly to all commissioners - no concerns raised.

##### **Areas for Further improvement**

Rainbows has developed a continuous quality improvement plan, which is informed by incidents, complaints, audit results and feedback. This is monitored through the CQAC.



## Quality Account 2022/23

### Children, Young People & Carer's:

The feedback survey was sent to all families that had accessed the hospice in the last year. The response rate was 18%.

How likely are you to recommend Rainbows to friends and family if they needed similar care?



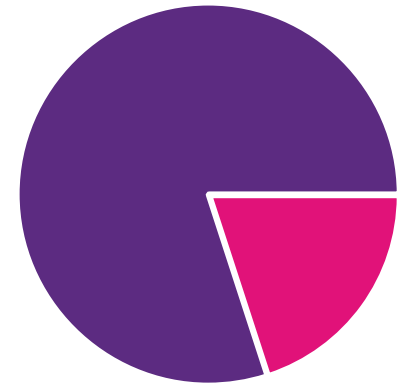
Extremely likely  
Likely

The care and support Rainbows offers the family is:



Very good  
Good  
Okay

The care your child/young person has received whilst at Rainbows is:



Very Good  
Good

## Quality Account 2022/23

### Family comments:

- “I don’t know another place like this, my child gets professional care and he is happy to be there.”
- “Rainbows gives us a safe and supportive place to share our fears. Your advice and practical help is amazing. You make such a difference to us. We are more grateful that you will ever know. Thank You!”
- “The 11 am pick up time at the end of a respite stay can be a problem.”
- “Knowing someone is there to help means a lot.”
- “The Zoom activities are fab!”
- “He loves having a bath at Rainbows and always enjoys a swim – I would be keen to know if he could access the pool when he is not staying.”
- “The facilities are wonderful, the staff are professional, efficient and friendly.”
- “The support is brilliant and it gives me a little break to gather myself and start afresh each time.”
- “Stayed at Rainbows for pain management and also as a family for respite. We have felt listened to, treated with kindness and felt relaxed during our stay.”
- “Even if we do not access stays or groups we have not been ignored or dismissed.”

### Complaints, Concerns & Compliments

Complaints	0
Concerns	2
Compliments	29

One of the Informal complaints / concerns was related to missing equipment and was resolved quickly with an apology to the family. The second one was following an error in administration of a feed / medication and following some changes to checking processes, the family were satisfied this was resolved for the future.

There have been 29 compliments over the last year. These have come from families, siblings, young people and professionals and have been captured in a variety of ways; via feedback forms, our white board, email and verbally. A flavour of some of our feedback is below.

“The thing I like about Rainbows is everyone knows me, I have my own base and it is fun!” - A Rainbows Sibling

“We feel safe, independent and listened to when we stay at Rainbows” - Rainbows Young Person.

“You helped me be the Mummy my Baby needed even in the hardest time” - Parent of a baby being supported in Hospital by our Neonatal Palliative Care Nurse Specialist.

## Part Six

### Review of Quality Performance

#### Quality Schedule

#### Hospice Safety Indicators

Hospice Safety Indicator	2021 / 2022	2020 / 2021
Number of patient safety related incidents/accidents, including medication errors (April 2019 – March 2020)	Total incidents = 146* Clinical incidents = 61 Near Misses = 22 Medication errors = 85 Controlled Medication errors = 13	Total incidents = 113 Clinical incidents = 72 Near misses = 16 Medication errors = 41 Controlled Medication errors = 3
Number of patients who developed category 3 and 4 pressure ulcers in our care	0	0
Infection Prevention and Control rates:	2	3
Total number of children admitted with known infection. This includes:		
• Number of C-Dif	0	0
• Number of MRSA	2	1
Total number of children who developed symptoms whilst staying at the hospice. This includes:	0	0
• Number of C-Dif/CRO	0	0
• Number of MRSA/CRO	0	0

\* excludes near misses



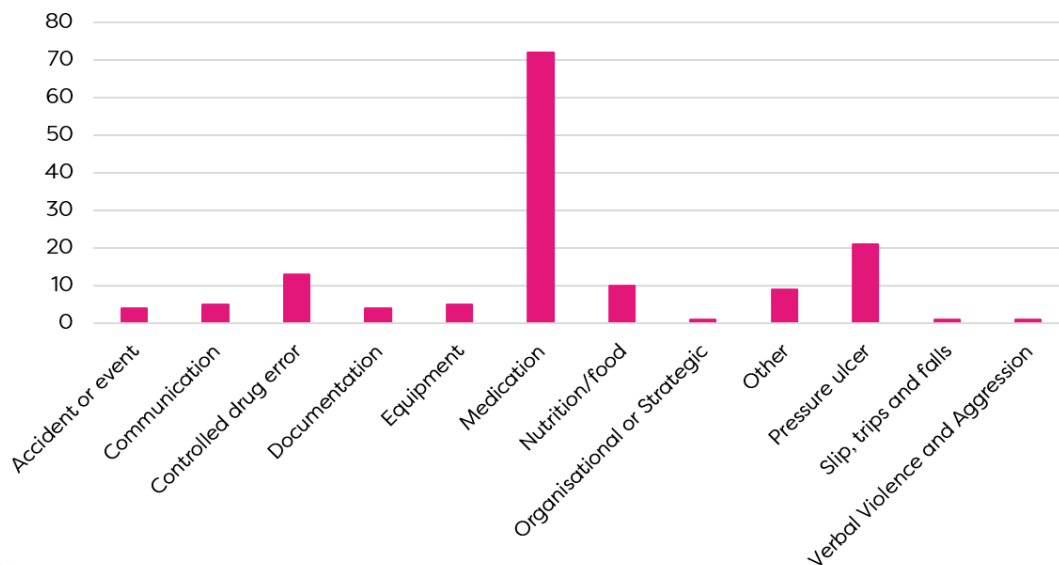
## Quality Account 2022/23

### Incident Reporting (Data from Datix from April 2021 – March 2022)

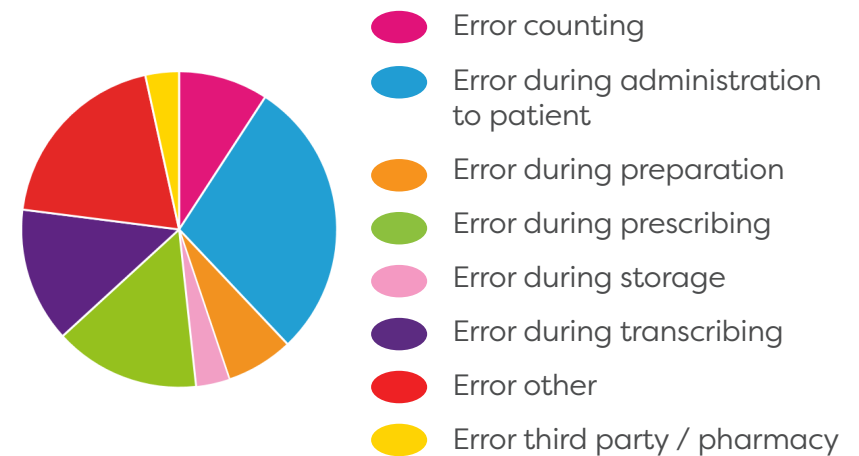
The increase in incidents from last year reflects the increase in activity as the world begins to emerge from the global COVID-19 pandemic and the dependency of the children and young people being admitted to the Hospice. It also reflects the excellent reporting culture at Rainbows. The chart below shows that our highest single area of incidents is medication which is to be expected as administration of medication is our highest risk and complexity intervention. Reporting of other clinical incidents such as noting of existing pressure ulcers on admission, the second highest area of incidents recorded, has meant that care can be continued and planned effectively with problems and safety concerns identified and resolved quickly to prevent deterioration.

Rainbows nurses administer in excess of 26,208 medication doses every year. The pie chart below drills down to the categories of medication errors to focus the areas for improvement as storage and administration of medications. Administration errors have remained largely consistent and reflect the volume of administrations. 84 of the total medication errors including 13 involving controlled drugs were no or low harm minor errors, with one error being moderate. A recent “Think Storage. Think Expiry” campaign has been launched to improve the incidence of wrong storage errors (13 in total for the year). Although relatively low numbers of errors, all errors are fully investigated and learning put into practice to minimise the same errors occurring again.

**All Clinical Incidents including Medication by Category  
April 2021 to March 2022**



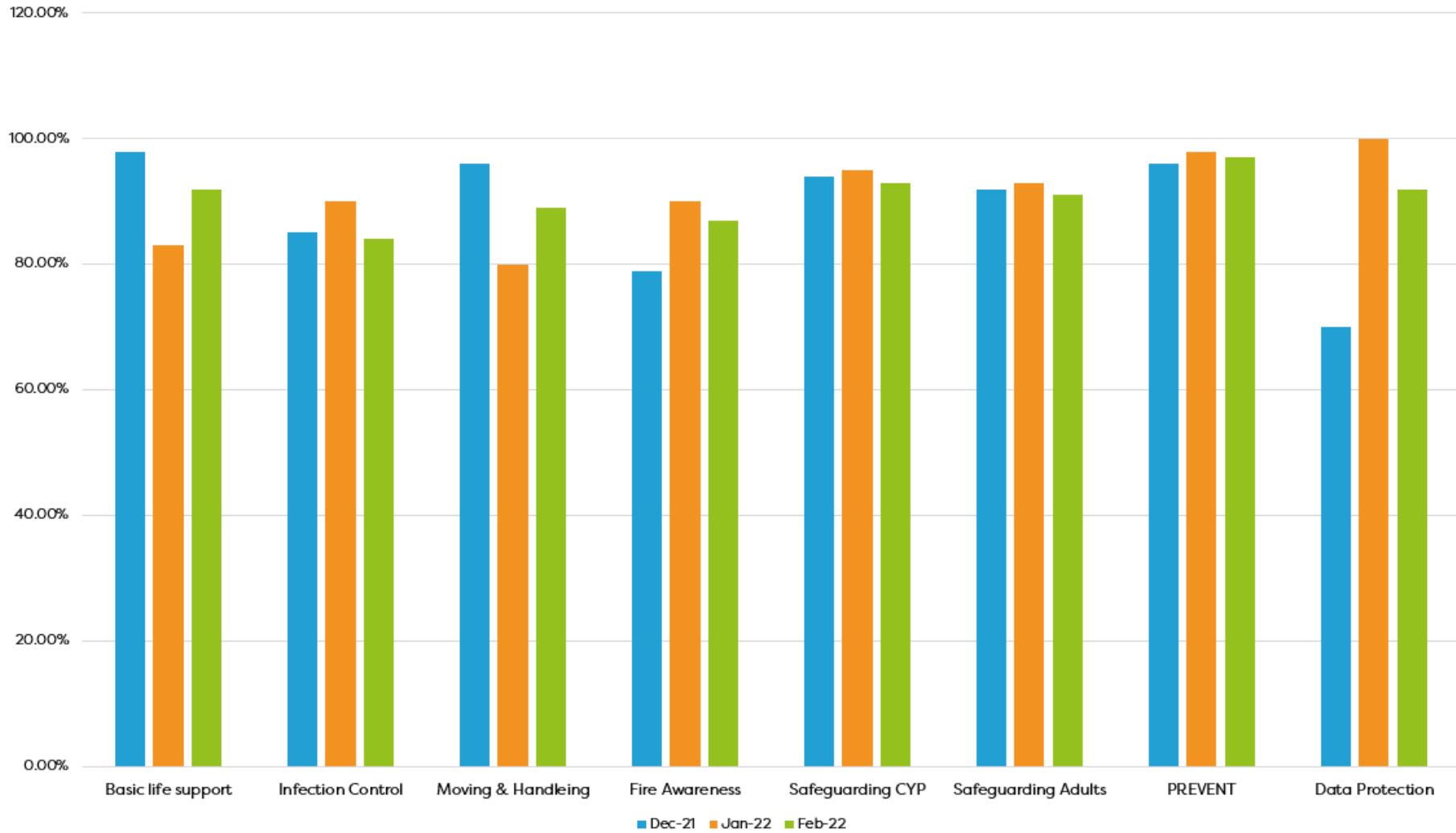
**Medicines Incidents by Stage at which it occurred.  
April 2021 - March 2022**



## Workforce

### Mandatory Training:

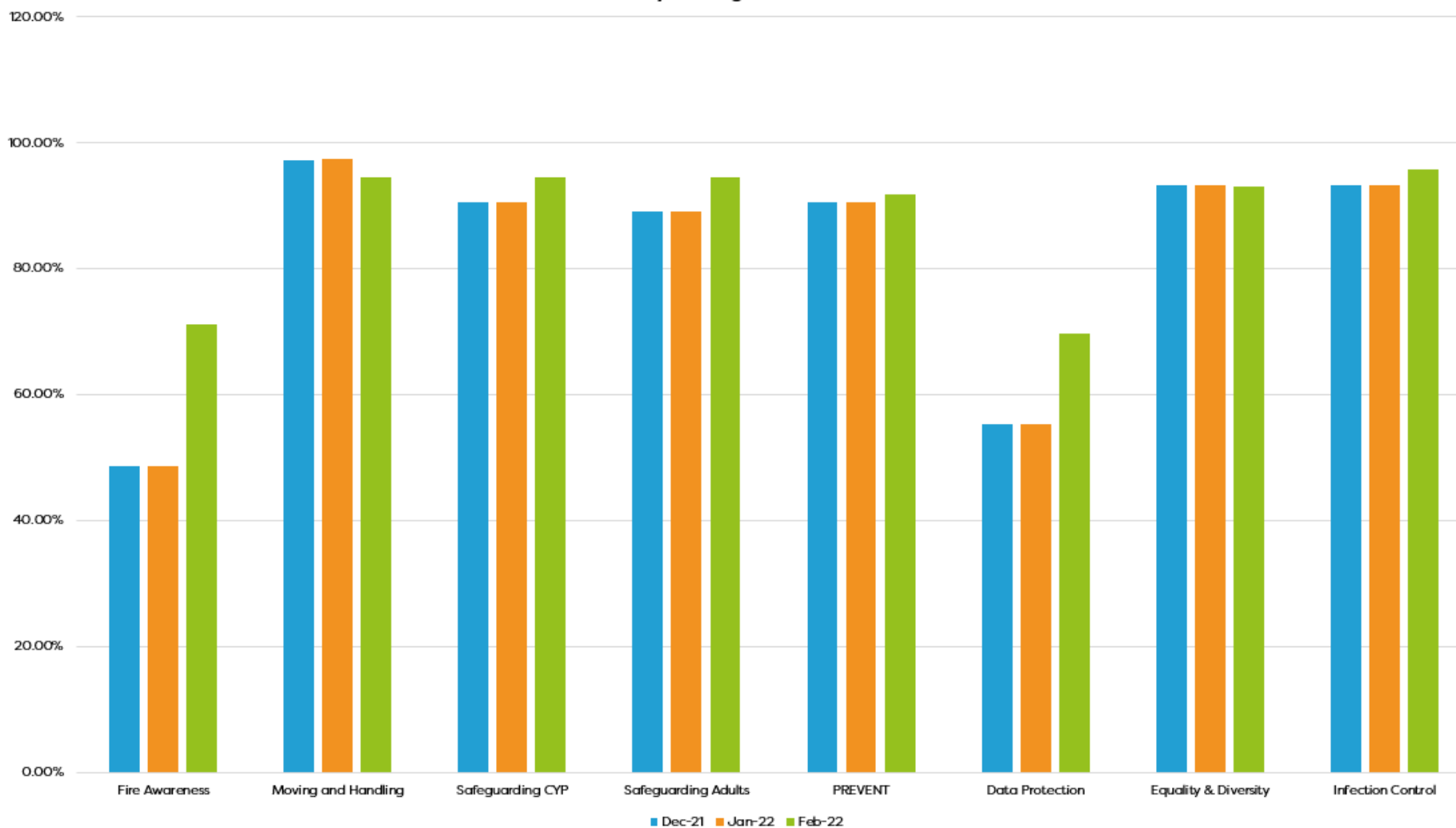
**Mandatory Training - Clinical Staff**



## Workforce

### Mandatory Training:

**Mandatory Training - Non-Clinical Staff**



### Equality, Diversity & Inclusion Strategy

Rainbows is committed to ensuring that we proactively advance equalities by ensuring an inclusive and supportive workplace. The Equality Diversity and Inclusion Strategy is being reviewed and updated following the appointment of a new Director of People. Our Equality Statement which is reflected in all our staff contracts which reference diversity and outline our employee's responsibilities.

Rainbows have a number of HR policies that support all of the above. Examples include; Equality Diversity and Human Rights Policy, Grievance Policy and Procedure, Transgender and Transitioning Policy and the Whistleblowing Policy.

In 2020, Rainbows introduced the Disability Passport and a comprehensive guide for managers on how to provide a personalised approach alongside the relevant policies and procedures in relation to equality, disability and reasonable adjustment during employment.

### Freedom to Speak Up

From recommendations in the '*Learning not Blaming*' report (2015) Rainbows appointed an independent Freedom to Speak Up (FTSU) Guardian for the charity and we have a designated board lead for Freedom to speak up.

The FTSU Guardian role is available for staff to feel safe to speak out about patient safety, as well as learning lessons by listening to those who have experiences to share, both positive and negative. The FTSU Guardian provides a yearly report to the Board of Trustees. Our Public Interest Disclosure (Whistle Blowing) Policy has been changed to include the FTSU roles and Rainbows have implemented this across the charity.

Our FTSU service was reviewed in 2021 and has been developed to ensure it continues to meet the needs of our staff and is effective.







## Quality Account 2022/23

### Safeguarding

Safeguarding Children, Adults, Mental Capacity and Deprivation of Liberty Safeguards policies were all reviewed during 2021. Updates to procedures and learning from serious case reviews are disseminated to Rainbows staff via a robust process of training and safeguarding specific supervision sessions, and all clinical staff demonstrate their understanding and skill level through completion of 1:1 sessions using the safeguarding competency framework commensurate to their roles and based upon The Royal College of Nursing Intercollegiate Guidance for both children and adults. Safeguarding training is mandatory for all staff and delivered through a system of blended learning, combining e-learning and face to face training. Compliance has risen significantly within the past 12 months and a process has been put in place to ensure compliance remains above 90%.

Rainbows Safeguarding Lead receives monthly supervision from The Head of Safeguarding for UHL hospitals and also sits on UHL Safeguarding Committee. Rainbows Care Team receive weekly safeguarding group supervision; Rainbows Nurses in Hospitals receive monthly group safeguarding supervision and Rainbows Clinical Leadership Team receive bi-monthly group safeguarding supervision..Rainbows Family Support Team access 1:1 safeguarding supervision when required. Rainbows has two Safeguarding Link Nurses on the Care Team who are supported by the Safeguarding Lead.

The Voice of the Child & Young Person Survey was adapted from one administered by UHL Safeguarding Team and as well as capturing data around quality it also asks children and young people to identify their involvement in their own admission and whether they have had the opportunity to speak with Rainbows staff without their parents/carers being present.

The Safeguarding Assurance Template (SAT) was requested by Derbyshire CCG and submitted in August 2021. Leicester, Leicestershire & Rutland CCG SAT will be submitted in April 2022 (Quarter 1).

Rainbows is a trusted partner within Leicester, Leicestershire and Rutland Safeguarding Children's Partnership Board and is named within the multi-agency Information Sharing Agreement.

### Duty of Candour

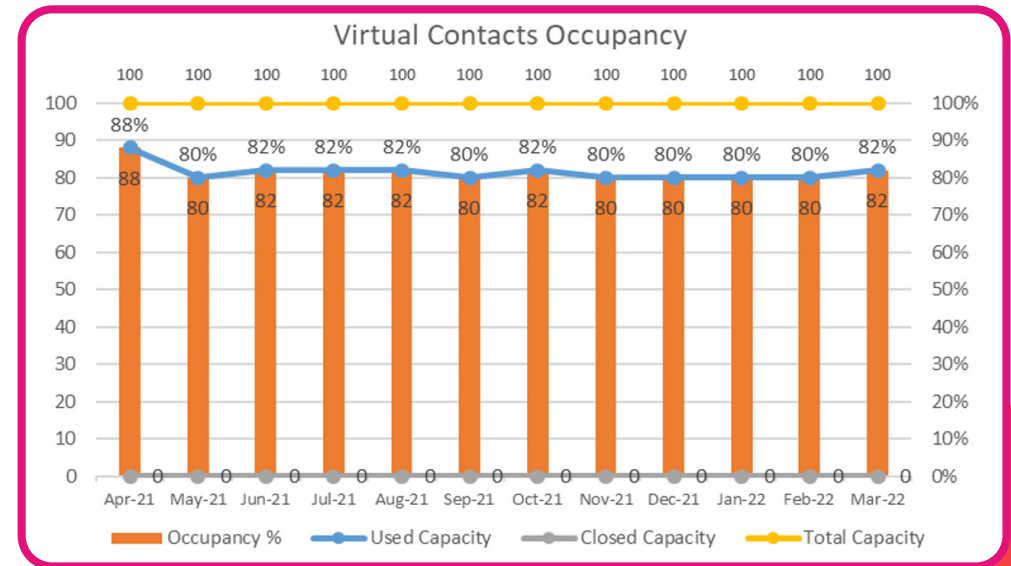
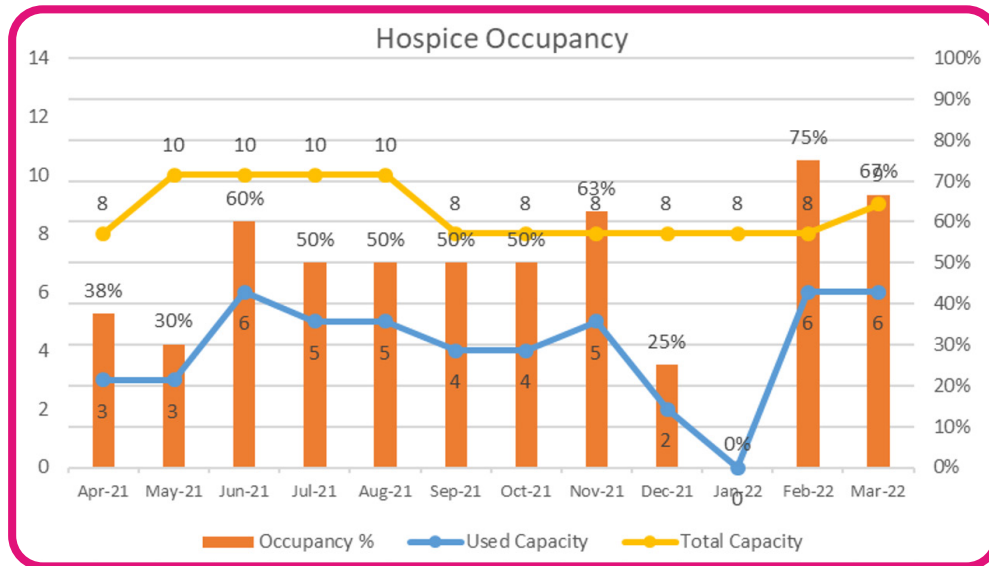
Rainbows follows the Duty of Candour Process for all incidents involving children and young people in our care.



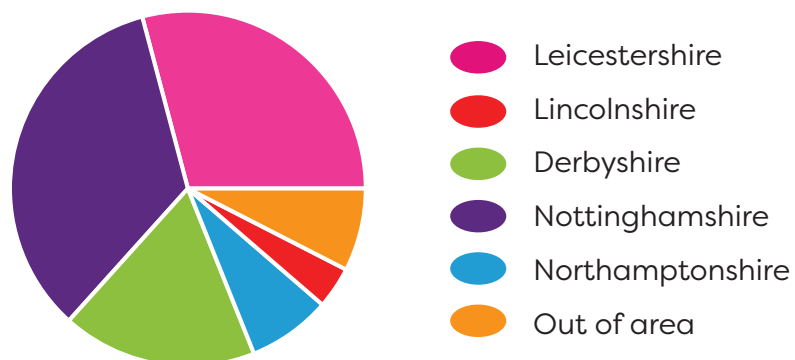
# Quality Account 2022/23

## 2021/22 Activity Report

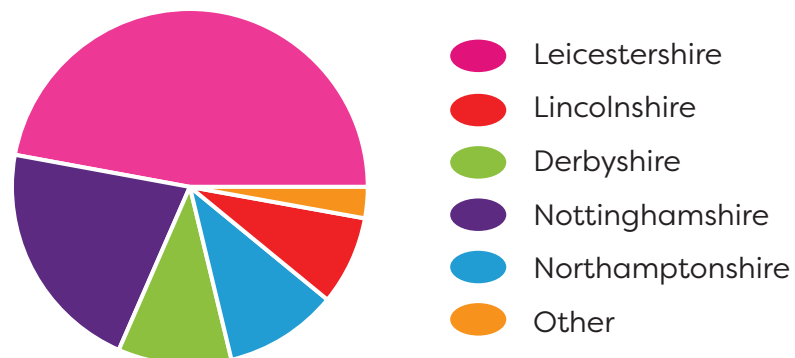
At the beginning of the Pandemic all Health and Social Care providers were required to submit capacity and activity data through the National Capacity Tracker. The graphs below show Hospice Occupancy and Virtual activity provided by Rainbows.



**% Referrals by County in 2020**



**% Referrals by County in 2021**



**Number of children and young people who accessed Rainbows services by County**

County	Number of children and young people who used service last year
Leicestershire	172
Nottinghamshire	96
Derbyshire	63
Lincolnshire	29
Northamptonshire	33
Other	5
<b>Total</b>	<b>398</b>

**Age profile of children of young people who accessed Rainbows services last year**

	Number of children and young people who used service last year	Percentage of children and young people (%)
0 - 2	41	10.30
3 - 7	87	21.86
8 - 14	108	71.14
5 - 18	84	21.11
19 - 24	60	15.08
25+	18	4.52
<b>Total</b>	<b>398</b>	<b>100</b>

### Part Seven

#### Service Improvements - 2021/22

##### Hospice at Home

Building on the successful implementation of Home support last year we have now further developed this service, incorporating it into our core services. Hospice at Home enables children and young people who are deteriorating or dying to receive episodes of hospice care at home. This has increased the reach as families who have chosen not to access the hospice building are benefitting from this hospice care.

##### Hospital Nurses

There has been a large increase in referrals to Rainbows and more families have had access to specialist palliative care expertise to support the holistic care their child needs. These increases have been particularly noticeable in neonates and children with cardiac conditions.

##### Palliative care Multi-disciplinary Team Meeting

We have established a weekly virtual MDT that includes the Team at Rainbows (including the doctor) as well as the Rainbows Nurses in Hospital and the Specialist Paediatric Palliative Care Consultant. Attendance is very good and it has enabled effective communication between hospital and hospice regarding individual children, identifying unmet holistic needs and planning to address needs and resolve challenges. There is a clear link between this initiative and positive outcomes for children, young people and families,

##### Medicines management

2021 saw the Rainbows Medicines Management Just Culture Framework that was launched in September 2020, further embedded into practice. All medicines incidents are discussed at the Medicines Management meeting bi-monthly. The National Coordinating Council for Medication Error Reporting and Prevention Index for categorising medication errors algorithm is used to assess harm and the just culture framework which looks at behaviours and human factors is applied to inform action and learning, which is consistent and fair, this is then cascaded via a number of forums / formats including “incident on a page” and “Top 10@10” team briefing. Our recent “Think Storage. Think Expiry” campaign was launched to ensure the continued safe storage of medicines.

CD incidents are reported by our Controlled Drugs Accountable Officer to the Local Intelligence Network quarterly and learning shared with and from CDAO colleagues across the East Midlands.



## Part Eight

### The Board of Trustees Commitment to Quality

The Board has an active role in ensuring that Rainbows provide a high quality service in accordance with our Statement of Purpose, which is updated regularly and displayed in hard copy format at the hospice

Our Board of Trustees are fully committed to providing the best service for our children and young people in order to achieve our vision and aims. Rainbows has an established governance structure, a Clinical Trustee Chairs the Clinical Quality Assurance Committee, with members of the Board sitting on both our Clinical Quality Assurance Committee and our Corporate Governance Committee.

The Board of Trustees regularly reviews the structure of meetings across the charity to ensure the appropriate committees and groups are in place with clear lines of accountability and input from trustees as required. A recent Board Governance review has reported a good governance structure with some areas to be developed further. In addition, Rainbows have a comprehensive Risk Register which is monitored by the governance committees who regularly update the Board in relation to areas of high risk.

The Board has approved and supports Rainbows five year strategy to ensure we continue to deliver high quality, relevant and effective services to CYP and families across the East Midlands. The strategy has been developed in line with National evidence on the prevalence of CYP with life limiting and life threatening conditions.

The Board have approved and supported the Rainbows Covid-19 response in relation to adaptation of services and compliance with all Covid regulations and requirements.

The Board is confident that the treatment and care provided at Rainbows is of the highest quality, with an embedded culture of continuous quality improvement and learning whilst remaining cost effective and efficient.





## Part Nine

### Responses to Rainbows Quality Account

Leicester, Leicestershire and Rutland CCG say:

“Rainbows Childrens Hospice is a vital resource providing support through difficult times for children, young people and their families across the East Midlands. Within its broad scope is the invaluable work it achieves that is caring, compassionate, of a high standard and ambitious to achieve more; this is reflective of the commitment of all people in the Rainbows team.

Of particular note is the drive to continue to learn and make improvements to enhance the experience of children, young people, families and staff. Despite the restrictions of the last two years due to the global pandemic, Rainbows has been able to recruit and appoint new members to its team to improve the services it provides and also strengthen links with other organisations. The introduction of new IT systems to manage data and risk together with a refreshed clinical audit programme will enhance the high quality care already provided.

The Leicester, Leicestershire and Rutland CCG is proud to be associated with Rainbows and looks forward to continued involvement as well as viewing its sustained progress through the coming year.”





## Quality Account 2022/23

### Appendix 1

#### Audit Calendar 2022-2023

Month	Clinical		Corporate		Health & Safety	
	Audit	Quality Improvement	Audit	Quality Improvement	Audit	Quality Improvement
April	External Placement Audits External Controlled Drugs Audit	15 Step Challenge				
May					Control of Legionella	
June			Lottery			
July		15 Step Challenge	Shops - Finance		Shops - Health and Safety	
August						
September	Mattress Audit			Sit and See - Data Protection	Review of Coshh	
October		15 Step Challenge	Finance - Mid Year			Compliance with environmental policy
November	Tissue Viability Audit External Controlled Drugs Audit External Medication Storage Audit		Fundraising Audit		Security	
December	Uniform Audit					
January	Mixed Sex Accommodation	15 Step Challenge			Fire	
February			Gift Aid			
March	External Infection Prevention Control Audit			Sit and See - Reception	Safe Catering	

## Appendix 2

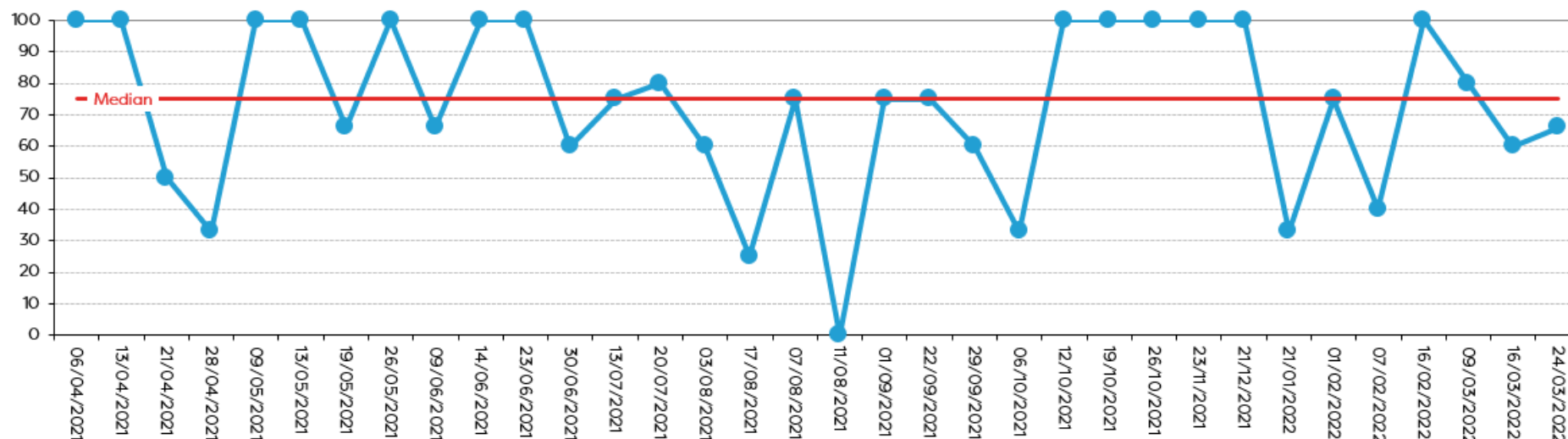
Clinical Audit	Outcome
Placement Audits	We are currently working with 7 universities to provide placements to students from nursing and physiotherapy backgrounds: Nottingham Trent, Nottingham, Derby, University of Leicester, De Montfort University, Keele and Staffordshire Universities. Audits are carried out by the universities annually and they have all been completed for this year.
External Medicines Storage Audit	An Audit was carried out in November 2021 by external Pharmacy Assistant from University Hospitals of Leicester (UHL). The audit findings were exemplary and no further action was required / no recommendations made. This is the second year in a row that our compliance has been 100% for stock medication. The annual update of nurses' signatures for purposes of ordering medicines from UHL was updated in Jan 2022.
Children and Adults Health Safeguarding Assurance Template	<p>This template outlines assurance against key safeguarding requirements for adults and children and to identify areas for development or where additional assurance is required.</p> <p>Rainbows demonstrated compliance with the Children Act 2004 and the Care Act (2015).</p> <p>Safeguarding at Rainbows is managed safely and effectively. Our Safeguarding Committee meets bi-monthly and reports are presented to the Clinical Quality Assurance Committee and Board of Trustees.</p>
Drug Storage Audit	Rainbows carry out audits every three months and have devised a tool to carry out audits, producing an action plan following each audit, if appropriate.
Drug Chart Audit	Weekly audit of Medicines Administration Records (Drug charts) is carried out in order to monitor standards on a continuous cycle and ensure continuous improvement in practice.
External Controlled Drugs Audit	<p>Audit carried out in November 2021 by external Pharmacy Assistant from University Hospitals of Leicester (UHL).</p> <p>The audit noted a neat Controlled Drugs register, expired Controlled Drugs stored correctly, wastage was well documented and Controlled Drugs stored as per policy within the designated locked Controlled Drugs cupboard. Discrepancies were logged and cross referenced in the register to the log sheet.</p> <p>The audit found our practice to be exemplary with no further action required. This is the second year in a row that our compliance has been 100% for CD's.</p>
Infection Prevention Audit	Infection Prevention and Control audits have continued to be carried out with Hand hygiene audits and PPE audits being carried out on a monthly basis increased as necessary during community outbreaks of COVID-19. Hand Hygiene and PPE compliance remained at 100% during 2021. A monthly "walk around" audit of the clinical area identifies any concerns or environmental issues which are then addressed working with our facilities and housekeeping teams. Compliance to standards within this audit has been 99% to 100%. Partnership working with UHL has continued throughout the pandemic and is returning to face to face support with a planned full audit in April 2022.

Clinical Audit	Outcome
Record Keeping Audit	<p>Rainbows continued to carry out weekly monitoring using a recognised clinical records audit template against NHS standard and criteria. Audit results have varied throughout the year with most compliance issues relating to missing signatures on the signature tracker, which will be resolved with electronic records.</p> <p>The record keeping policy was revamped and recirculated to the team and to new starters as a matter of course, along with a workbook and staff record keeping training in 2021 and awareness sessions and reflective discussions during line management 1-2-1s which is on-going</p> <p>Ongoing work continues to ensure accurate and complete patient records, including clear and concise evaluations of care, especially with the recent transition to electronic care records from February 2022. A new weekly record keeping audit has been drafted in light of the change, with the policy and workbook being updated to reflect the change. The formal weekly audit has been paused until May 2022 whilst the team transition to electronic records.</p>
Mattress Audit	<p>A full mattress audit by an external assessor did not take place in 2021 due to Covid-19, however, our housekeepers continue to monitor via monthly checks using the monitoring form and escalate any concerns. The external audit is planned for May 2022.</p>
Mixed Sex Accommodation	<p>Rainbows continues to be compliant with the requirement to support young people staying in a mixed sex accommodation environment as per the Mixed Sex Accommodation policy. The annual audit which seeks to ensure compliance against all standards set by the Department of Health found that due to the changes to the environment to ensure that CYP are being</p> <p>cared for in a COVID safe way, some processes were now different to those described in the policy, however children and young adults continue to be accommodated in separate areas. The Department of health requires all providers of NHS funded care to confirm that they are compliant with the national definition 'to eliminate mixed sex accommodation except where it is in the overall best interests of the patient or reflects the patient's choice'.</p> <p>Rainbows are committed to maintaining the privacy and dignity for males and females staying at the hospice. Rainbows have implemented a number of processes that support the sensitive management of males and females whose bedrooms are located in the same area of the hospice.</p>

## Quality Account 2022/23

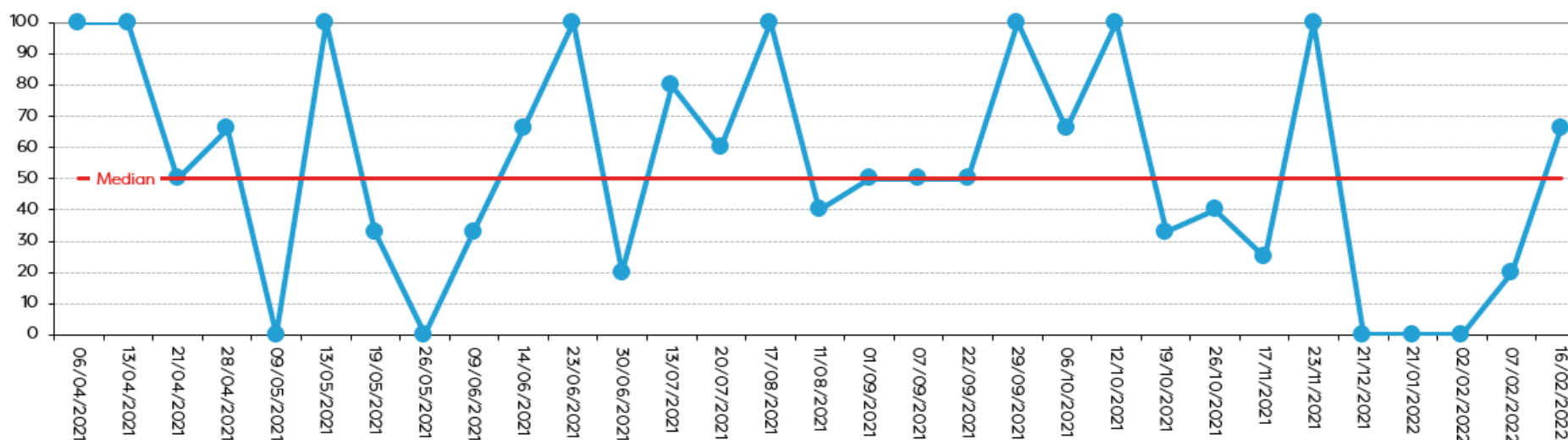
Percentage of Charts  
to Standard

**Drug Chart Audit April 2021 - March 2022**



Percentage of Records  
to standard

**Record keeping audit April 2021 to March 2022**





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Care Quality Commission Provide ID: 1-101728495

This Quality Account has been endorsed by the Hospice Board of Trustees



[rainbows.co.uk](http://rainbows.co.uk)

Rainbows is registered as Cope Children's Trust in England and Wales. Registered Charity No. 1014051.  
Registered Office: Lark Rise, Loughborough, Leicestershire LE11 2HS.